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McCorry, N. K., Scullion, L., McMurray, C. M., Houghton, R., & Dempster, M. (2013). Content validity of the Illness Perception Questionnaire-Revised for people with Type 2 Diabetes: A Think-Aloud study. *Psychology and Health*, 28(6), 675-685. <https://doi.org/10.1080/08870446.2012.746690>

**Published in:**  
Psychology and Health

**Document Version:**  
Peer reviewed version

**Queen's University Belfast - Research Portal:**  
[Link to publication record in Queen's University Belfast Research Portal](#)

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Content Validity of the Illness Perceptions Questionnaire - Revised among People with Type  
2 Diabetes: A Think-Aloud Study

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### **Acknowledgements**

We are grateful to Dr Paula McDonald and Dr Stephen Johnston (The Castle Practice, Carrickfergus, Northern Ireland) for their assistance in the recruitment of research participants.

### **Abstract**

**Objectives:** To access the cognitions of adults with type 2 diabetes whilst completing items on the Illness Perceptions Questionnaire – Revised (IPQ-R). To determine whether these cognitions are congruent with the meaning of items and subscales as interpreted by researchers and clinicians using the IPQ-R and to identify the nature and extent of problems that individuals experience when completing the IPQ-R.

**Design:** Participants (n=36) were recruited from a primary care diabetes clinic and a hospital diabetes clinic. They were asked to complete the IPQ-R using a ‘think-aloud’ methodology.

**Main Outcome Measures:** Transcripts were analysed to identify instances where participants expressed problems with item completion, or where there was inconsistency between verbal and written responses.

**Results:** The most problematic subscales were those of ‘personal control’ and ‘consequences’.

**Conclusion:** Generally, participants found the IPQ-R unproblematic. However, participants had problems with the concept of ‘cure’ and ‘symptoms’ in the context of type 2 diabetes, and with the negative phrasing used in some items. These findings have important implications for the interpretation of IPQ-R scores, particularly when the IPQ-R is used as the basis for individualised interventions among people with type 2 diabetes.

**Keywords:** Illness Perceptions Questionnaire; IPQ-R; Type 2 diabetes; Think-Aloud; Illness Representations

A large body of research has focused on the illness perceptions component of Leventhal's Common Sense Model (Leventhal, Meyer & Nerenz, 1980). The research generally demonstrates that illness perceptions explain a significant proportion of the variance in physical and psychological outcomes in a range of illnesses (Dempster et al., 2011a; Dorrian, Dempster & Adair, 2009; Glattacker, Opitz & Jäckel, 2010; Kaptein et al., 2010). The relationship between illness perceptions and both psychological and physical outcomes has been well established among adults with Type 2 diabetes (French et al., 2008; Lawson, Bundy, Belcher & Harvey, 2010; Searle, Norman, Thompson & Vedhara, 2007a; Searle, Norman, Thompson & Vedhara, 2007b; Searle et al., 2008; Skinner et al., 2006; Skinner et al., 2011; Sultan, Attali, Gilberg, Zenasni & Hartemann, 2011), and the findings of this research have been posited as a basis for interventions to improve well-being among this population.

The questionnaire most commonly used to assess illness perceptions is the Illness Perception Questionnaire-Revised (IPQ-R) (Moss-Morris et al., 2002). The IPQ-R assesses 9 illness perceptions: identity (perceptions of symptoms associated with the illness), consequences of the illness, cause of the illness, illness coherence (described as the person's perceptions of the extent to which they understand the illness), timeline cyclical (the perception of the cyclical nature of the illness across time); timeline acute/chronic (the person's perception about the illness passing quickly or not), personal control (perceptions of the person's ability to control the illness), treatment control (perceptions about the effectiveness of any treatment or the effectiveness of medical personnel to control the illness), and emotional representations (the extent to which the person's illness makes them experience symptoms of anxiety or depression). Moss-Morris et al. (2002) provide evidence for the validity and reliability of these dimensions when tested among a group of 711 people from 8 different illness populations. Although this evidence is convincing and includes

people with diabetes, the evidence for validity (and reliability) is not presented separately for the different illness groups. Therefore, there is no published information about the psychometric properties of the IPQ-R when used among people with Type 2 Diabetes specifically. This is an issue of concern for anyone wishing to use the IPQ-R among people with Type 2 Diabetes, as the interpretation and grouping of items on the IPQ and the IPQ-R has been shown to differ among different illness populations (Cabassa, Lagomasino, Dwight-Johnson, Hansen & Xie, 2008; Hagger & Orbell, 2005; Fleming, Martin, Miles & Atkinson, 2009; Giannousi, Manaras, Georgoulas & Samonis, 2010; Heijmans & de Ridder, 1998; Hirani, Pugsley & Newman, 2006). Furthermore, French and Weinman (2008) have advocated that some of the items on the IPQ-R might need to be adapted for specific illness populations, such as people with diabetes, and that there is a need to engage in a process of interview-based research to identify which items might require amendment. In other words, it is important to know whether the people who complete the questionnaire are interpreting the items on the questionnaire in the same way as they are interpreted by researchers and designers of interventions. For example, research among adults with Type 2 Diabetes has indicated that perceptions of control over diabetes are an important predictor of quality of life (Skinner et al., 2006). Yet, there is no point designing an intervention aimed at modifying individuals' perceptions of control over their diabetes unless we know what individuals understand by the items that purport to measure perceptions of control. It is this element of content validity that is the focus of the present study (see Streiner & Norman, 2001, pp.146-147 for a discussion of content validity).

There are a number of cognitive interview techniques which are useful methods to examine the potential problems with individual items on a questionnaire (see Willis, 2005, for a discussion). One commonly used method in psychology is the 'Think Aloud' method (van Someren, Barnard & Sandberg, 1994), which requires participants to verbalise their

thoughts as they undertake a task (completing a questionnaire in this case). Consequently, the Think Aloud method enables researchers to access the cognitive processes underlying a particular action (choosing a response to an item on the questionnaire), and therefore provides some insight into the interpretation of the questionnaire items by the respondent. This method has been used previously to investigate the manner in which people respond to items on questionnaires (Boeije & Janssens, 2004; Darker & French, 2009; French & Hevey, 2008; Westerman et al., 2008), including a think-aloud analysis (van Oort, Schröder & French, 2011) of the brief version of the IPQ (Broadbent, Petrie, Main & Weinman, 2006).

The aim of the present study is to access, using the Think-Aloud method, the cognitions of adults with Type 2 Diabetes whilst completing items on the IPQ-R, to determine whether these cognitions are congruent with the meaning of items / subscales as interpreted by researchers and clinicians using the IPQ-R (as originally conceptualised by authors of the IPQ-R).

## **Methods**

### **Participants**

Participants were recruited from a primary care based diabetes clinic and a hospital based diabetes clinic. Patients who were scheduled to attend these clinics at the time of data collection, and who met the study inclusion criteria ( $n=205$ ) were sent information about the study by post. Patients satisfied the inclusion criteria if they were over 18 years of age and had been diagnosed with Type 2 Diabetes at least one year prior to data collection. Those who responded ( $n = 42$ ) were contacted to arrange a suitable time for participation. Data collection was completed with 36 participants. In four cases participants had significant difficulty in expressing their thought processes verbally, and their data was subsequently excluded from further analyses. Consequently the final study sample consisted of 32 participants (50% male). The mean age of participants was 64.77 years (SD 10.00). Mean

time since diagnosis was 7.69 years (SD 6.31). Diabetes treatment was by diet and lifestyle modification alone (n=5; 15.63%), oral medications / lifestyle modification (n=18; 56.25%), and a combination of insulin injections / lifestyle modification / oral medications (n= 9; 28.13%). Participants current mean HbA1c was 7.74% (61mmol/mol), ranging from 5.50% (37mmol/mol) to 10.10% (87mmol/mol). The presence of at least one diabetes-related complication (diabetic neuropathy, diabetic retinopathy, erectile dysfunction) was indicated in the medical notes of seven participants (21.88%).

### **Procedure**

Before commencing the IPQ-R think-aloud task, each participant was read the following instructions, adapted from a set of 'best practice' instructions for think-aloud studies (Ericsson & Simon, 1993; Green & Gilhooly, 1996):

We are interested in what you think about when completing the questionnaire. In order to do this, I am going to ask you to THINK ALOUD as you work. What I mean by 'think aloud' is that I want you to tell me EVERYTHING you are thinking from the time you read the instructions and the first item until you reach the end of the questionnaire. I don't want you to plan out what you say or try to explain to me what you are saying. Just act as if you are alone in the room speaking to yourself. It is most important that you keep talking. If you are silent for any long period of time, I will ask you to talk. Please try to speak as clearly as possible, as I shall be recording you as you speak. Do you understand what I want you to do?

Participants were further familiarised with the think-aloud method using a warm-up task, during which participants responded (using a 5 point Likert scale similar to that used by the IPQ-R) to questions about their dental care. Following the warm-up task, any further questions were clarified before the IPQ-R was administered. Once participants began the task they were not interrupted unless they fell silent for 10 seconds, at which point the researcher

prompted them to ‘keep talking’ or ‘tell me what you’re thinking’, in accordance with think-aloud protocol (Darker & French, 2009; Ericsson & Simon, 1993; Green & Gilhooly, 1996). Data collection sessions lasted between 30 minutes and one hour. The IPQ-R think-aloud session was audio-recorded, and all speech during the task was transcribed verbatim. The IPQ-R version used was the full version adapted for diabetes, as published on the IPQ-R website ([www.uib.no/ipq](http://www.uib.no/ipq)).

### **Analysis**

Analysis of the data followed a content analysis approach. Five transcripts were used to generate a coding framework by the first and second authors. Codes were generated from any discrepancies in verbal and written responses, and verbal difficulties expressed while completing the questionnaire. The coding framework was discussed and revised in consultation with the remaining authors. The first and second authors then independently coded the data from a further five participants and a kappa statistic was calculated to assess the level of agreement between the raters. This is similar to the procedure followed by Darker and French (2009). Inter-rater reliability was found to be high ( $\kappa = .857$ ,  $p < .001$ ). The coding framework was independently applied by the first and second authors to the entire dataset, and discrepancies were resolved through discussion. The final coding framework consisted of seven codes. The first code represented ‘no problems’ (indicating that there were no problems experienced with this item by the participant). The remaining six codes were considered to represent problematic responses for the interpretation of an item: ‘not applicable’ (participants expressed the opinion that the item was not appropriate to their circumstances), ‘incongruent response’ (where written and verbal responses were clearly incongruent), ‘different question’ (participants answered a different question to that which was asked), ‘confusion’ (participants indicated that they did not fully understand the content of the item), ‘Missing’ (the item was omitted completely), and ‘repeated question’



(participants repeated or stumbled over the question several times as a result of difficulty in understanding the item because of its structure). Responses were coded as ‘no problems’ unless there was think-aloud data to the contrary.

### Results

Table 1 provides details of the frequency and nature of problems experienced by participants for individual items of the IPQ-R, where five or more problems were identified. A table displaying the results for all items can be found online.

#### Location of Table 1

The most problematic item was ‘cause: altered immunity’. Almost 60% (n=19) of participants expressed confusion about the meaning of this term.

‘Incongruent response’ accounted for problems with several items. For example, 12 participants (37.5%) indicated in their verbal response to the item ‘my diabetes does not have much effect on my life’ that diabetes did not impact on their life, but would then choose the ‘disagree’ response on paper (or vice versa). A substantial proportion of participants indicated that the items ‘my treatment will be effective in curing my diabetes’ and ‘my symptoms come and go in cycles’ were not applicable, as they did not endorse the concept of a cure for diabetes and they did not perceive themselves to have overt symptoms. The think-aloud data also revealed some interesting examples of how responses to IPQ-R items were sometimes considered in relation to the individual’s appraisal of their own coping responses. This was particularly common in response to consequence items. For example low scores in response to the ‘consequences’ item ‘my diabetes strongly affects the way others see me’ were found to reflect two distinct and contradictory beliefs. The first of these considers diabetes to be a common illness with little associated stigma which therefore does not impact on other people’s perception of the individual. The second response type which also results in a low ‘consequences’ score represents the belief that diabetes will have little effect on others’

perceptions of the individual because the participant has chosen to withhold this information from others (reflecting their coping response). It is sometimes clear that the individual has chosen this coping response *because* they believe their health status would affect how others see them.

A lot of people don't know. My employers don't know I have it... they'd have you straight off the job ... Well a lot of firms and companies would say that they are not prejudiced against this here, but you wouldn't be there two months before they'll find some reason to get you out [P23 endorses 'disagree' option]

Similarly, there are quite distinct profiles of beliefs in relation to the consequences of diabetes represented by low scores on the item 'my diabetes is a serious condition'. Some participants produced low scores on this item because they did not perceive their illness to be serious or life-threatening, whilst others produced low scores because they had appraised the impact of diabetes in relation to their own efforts at behavioural management (a coping response).

My diabetes is mild... and it doesn't affect my eyes or kidneys or anything. I think I'll probably die of something else. I'm overweight and I have angina... [P42 endorses 'disagree' option]

My diabetes is a serious condition, illness - well yes and no. I've had it that long I'm working at it, so no I don't look on it as a serious condition, but maybe I should but because it's under control I know it doesn't have to be serious. So ...em...strongly disagree ...oh maybe. Whether to agree or disagree because in a way it's controlled so it doesn't have to be [P25 endorses 'disagree' option]

Whilst both response types are consistent with the belief that diabetes will have less severe consequences on the individual, and were not coded as problems, they do represent quite distinct patient profiles.

A similar phenomenon was observed in response to the ‘timeline acute / chronic’ item ‘my diabetes will improve in time’, with some participants making reference to the effect of their own efforts or treatment effects on their experience of the illness over time.

it’s down to me if it gets better, my behaviour, taking medication, doing what I’m told...symptoms can improve... it’s not the diabetes that’s improved [P40 endorses the ‘agree’ option]

Hence the above participant produced a low score on this ‘timeline acute/chronic’ item (representing a belief that diabetes has an acute timeline) because they considered the consequences of their own coping efforts in improving their experience of the illness, whilst still endorsing the chronic nature of diabetes in their verbal response.

### **Discussion**

French and Weinman (2008) predicted that items on the IPQ-R that addressed the concepts of symptoms and cure could be problematic when the questionnaire is used among people with diabetes. The present study provides empirical support for these assertions. The questionnaire used in the study is the one adapted for diabetes and available on the IPQ-R website. The adaptation seems to simply replace the word ‘illness’ with ‘diabetes’ and the present study suggests that this is insufficient.

The present findings suggest that the concepts of cure and control be measured separately for populations with type 2 diabetes. In fact, perceptions of ‘treatment control’ may be even more multi-faceted among people with diabetes, incorporating beliefs about the effectiveness of treatment to control diabetes and the effectiveness of treatment to prevent complications – beliefs which are represented by distinct factors within the Diabetes Illness Representations Questionnaire (DIRQ; Skinner et al., 2003).

Our findings also suggest that amendments are required to items that address symptoms. After diagnosis and initiation of treatment, people with diabetes are less likely to

experience overt symptoms of the illness, especially in the absence of any diabetes-related complications. In addition, where respondents within the current study did verbalise their thoughts in relation to symptoms, these were often symptoms of treatment (rather than the illness per se), such as hypoglycaemia. The perceived symptoms of treatment may be an important aspect of illness representations to be measured among people with diabetes as it is likely to impact particularly on treatment adherence behaviours, as well as perceptions of control and psychological wellbeing. Whilst these representations about the impact / symptoms of treatment may be captured to some extent by items within the ‘consequences’ scale of the IPQ-R, consideration should be given to the distinction between both the consequences and symptoms *of the illness*, and the consequences and symptoms *of treatment* for people with diabetes.

Whilst the problems described above may be specific to populations with diabetes, other more generic issues of understanding were noted in the think-aloud data, which are likely to have more universal implications. Firstly, participants appeared to experience problems with items that used negative phrasing. The inclusion of negatively worded items in a questionnaire might be considered good practice, in an effort to address problems such as response sets, and thereby minimise systematic error. However, agreeing, and especially disagreeing with negatively worded items adds a degree of cognitive complexity to the task of responding to a questionnaire, and performance on negatively worded items has been found to be related to verbal ability (Marsh, 1996). On balance, it appears that negatively worded items might lead to more problems than they solve and so should probably be avoided in the construction of questionnaires (Roszkowski & Soven, 2010).

In addition, the concept of ‘altered immunity’ was not widely understood by our participants.

Some interesting variability was observed in participants' verbal responses, such that the same score on items could reflect very different profiles of illness representation, dependent on whether the respondent reflected on their own ability to cope with the potential consequences of the illness before endorsing their response to these items. Dempster & McCorry (2012) suggest that the responses to the items on the consequences factor represent the outcomes of an appraisal process, i.e. perception of the consequences after a consideration of the resources available to cope with these consequences. This observation may help to explain why the majority of research in this area has found no mediating role for coping in the explanation of psychological wellbeing (Hagger & Orbell, 2003; Dempster et al., 2011b).

It is important to note that the success of the think-aloud method is dependent upon participants' ability to verbalise their cognitions, and not all participants did this consistently throughout the task (as is common in think-aloud research). Hence, problems with the IPQ-R may be underestimated in this study because responses were coded as unproblematic unless there was think-aloud data to the contrary. In addition the coding of problems was more conservative than the approach taken in other research (e.g. van Oort et al., 2011) in that simply stumbling or re-reading an item was not coded as a problem. The 'repeat question' code was only applied where there was clear evidence that the participant had difficulty understanding the question.

Given that approximately 20% of those approached agreed to participate there is a potential bias in the sample. However, the characteristics of the sample appear representative of the population of people with type 2 diabetes in the UK, in terms of age, gender and treatment profile (Diabetes UK, 2011).

Whilst for the majority of items on the IPQ-R, no problems were identified, this study has highlighted that similar scores on items/subscales may reflect very different cognitions about diabetes. This has important implications for the interpretation of scores by researchers

and clinicians, particularly when the IPQ-R is used as the basis for individualised interventions among people with type 2 diabetes.

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